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1 SB256
2 5PJJ636-1
3 By Senators Smitherman, Singleton
4 RFD: Children and Youth Health
5 First Read: 21-Mar-24



4 SYNOPSIS:

5 Under existing law, each newborn child is
6 screened for certain heritable diseases and conditions,
7 as determined by the Alabama State Board of Health.

8 This bill would require the State Board of
9 Health to add any condition on the Recommended Uniform
10 Screening Panel (RUSP).

11 This bill would require the State Board of
12 Health to adopt rules relating to the use of the
13 Newborn Screening Panel.

14 This bill would provide a timeline for
15 conditions with RUSP approval to be included on the
16 panel and would require a written report to the State
17 Health Officer if the timeline is not met.

18 This bill would also provide that the duties of
19 the State Laboratory relating to testing for certain
20 heritable diseases and conditions are contingent on the
21 availability of funding.

22
23
24 A BILL

25 TO BE ENTITLED

26 AN ACT

27
28 Relating to newborn screening; to amend Section



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22-20-3, Code of Alabama 1975; to add Section 22-20-3.2 to the Code of Alabama 1975; to provide Legislative Findings; to require conditions on the Recommended Uniform Screening Panel (RUSP) to be included on the Newborn Screening Panel; to provide a timeline for the addition of RUSP-approved condition on the panel; to require the State Board of Health to adopt rules relating to the newborn screening program; and to condition testing for heritable diseases and conditions by the State Laboratory on the availability of funding.

BE IT ENACTED BY THE LEGISLATURE OF ALABAMA:

Section 1. (a) This act shall be known and may be cited as the Zachary Thomas Newborn Screening Act.

(b) The Legislature finds and declares that:

(1) Babies born in Alabama are currently screened for some, but not all, conditions included on the United States Department of Human Services' Recommended Uniform Screening Panel (RUSP).

(2) New conditions are added to the RUSP on a regular basis, and the Department of Public Health is firmly committed to adding RUSP conditions to the state's newborn screening panel.

(3) It is in the best interest of the state to continue to support the State Laboratory and its important mission of newborn screening.

Section 2. Section 22-20-3, Code of Alabama 1975, is amended to read as follows:

"§22-20-3

(a) For the purposes of this section, the following



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terms have the following meanings:

(1) BOARD. The Alabama State Board of Health.

(2) NEWBORN SCREENING PANEL or PANEL. The list of conditions that the State of Alabama screens for as part of the Newborn Screening Program.

(3) NEWBORN SCREENING PROGRAM or PROGRAM. The Department of Public Health's program that tests newborn children for conditions on the Newborn Screening Panel and identifies newborn children that may have those conditions.

(4) RUSP. The Recommended Uniform Screening Panel recommended by the Secretary of the Department and Health and Human Services for states to screen as part of their newborn screening programs.

(5) STATE LABORATORY. The Bureau of Clinical Laboratories within the Department of Public Health.

~~(b) It shall be the duty of the~~ The administrative officer, ~~or other persons~~ individuals in charge of each institution caring for ~~infants~~ newborn children 28 days ~~or less of age~~ old or younger, ~~or~~ the physician attending a newborn child, or the person individual attending a newborn child that was not attended by a physician ~~to~~ shall cause to have administered to every ~~such infant or~~ newborn child in his or her care a reliable test for conditions on the Newborn Screening Panel, including ~~hypothyroidism and a reliable test for phenylketonuria (PKU), such as the Guthrie test, or any other test considered equally reliable by the State Board of Health and a reliable test for sickle cell anemia, sickle cell trait, and/or abnormal hemoglobin and such other tests~~



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relating to mental retardation or other genetic, metabolic, or
other heritable diseases ~~and conditions~~ as ~~are designated~~
approved for inclusion on the Newborn Screening Panel by the
~~Board of Health~~ board, pursuant to Section 22-20-3.2, ~~,-~~
~~Provided provided~~, however, that the ~~Board of Health~~ board
shall designate only conditions that are detectable by mass
screening of newborn ~~infants~~ children. Initial mass screening
tests and the recording of results shall be performed by the
~~Public Health~~ State Laboratory ~~at such times and in such~~
~~manner~~ as ~~may be~~ prescribed by the ~~State Board of Health;~~
board and confirmatory tests shall be undertaken by ~~such~~
laboratory facilities as ~~are~~ designated by the attending
physician or parent; ~~provided, that no such initial.~~

(c) No screening or confirmatory tests shall be given
to any newborn child whose parent or parents object ~~thereto~~ on
the grounds that ~~such~~ the screening or tests conflict with
their religious tenets and practices. In the event a test is
not given to a newborn child on account of ~~such~~ objections by
~~the~~ his or her parent or parents, then no physician, nurse,
laboratory technician, ~~person~~ individual administering tests,
hospital, institution, or other health care provider shall be
liable for failure to administer the test.

~~(b)~~ (d) The ~~State Board of Health~~ board shall ~~promulgate~~
~~such~~ adopt rules ~~and regulations~~ as ~~it considers~~ necessary to
provide for the care and treatment of ~~those newborn infants~~
children whose tests are determined positive, including, but
not limited to, advising dietary treatment for ~~such infants~~
newborn children. The ~~State Board of Health~~ board shall



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~~promulgate~~ adopt any other rules ~~and regulations~~ necessary to effectuate ~~the provisions of~~ this section, including the collection of a reasonable fee for the newborn child screening program."

Section 3. Section 22-20-3.2 is added to the Code of Alabama 1975, to read as follows:

§22-20-3.2

(a) This section shall have the same definitions as Section 22-20-3, Code of Alabama 1975.

(b) The board shall adopt rules to administer the use of the Newborn Screening Panel, including the conditions for which screening is required. The Newborn Screening Panel shall include, but not be limited to, those conditions listed on the RUSP. Nothing in this act precludes the board from adding conditions to the Newborn Screening Panel that do not appear on the RUSP.

(c) (1) No later than 36 months following the approval and addition of a new condition to the RUSP, the board shall add the condition to the Newborn Screening Panel and implement and administer screening.

(2) Any condition added to the RUSP prior to January 1, 2024, shall be added to the panel by the board no later than October 1, 2027.

(3) In the event that a RUSP-approved condition is not added to the Newborn Screening Panel in the time frame required by this subsection, the board shall provide a written notice to the State Health Officer outlining the reasons for the delay. Following its presentation to the State Health



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141 Officer, the board shall post the same written notice on its
142 website.

143 (d) Testing for heritable diseases and conditions and
144 the services and facilities required for testing shall be
145 subject to the availability of funding and workforce in the
146 State Laboratory, as determined by the board.

147 Section 4. This act shall become effective on October
148 1, 2024.